Understanding factors associated with Australian mental health carers’ employment

Commissioned by Mind Australia Limited

Summary report
June 2018

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Acknowledgements

This work was funded by Mind Australia Limited under the Mind Carer Development Fund. The analysis used data drawn from the 2015 Survey of Disability, Ageing and Carers which was funded by the Australian Government Department of Health and conducted by the Australian Bureau of Statistics.

Many thanks to the Project Advisory Group established by Mind who provided advice on the scope and presentation of the analysis to improve its policy relevance: Amaya Alvarez, Sue Elderton, John Foley, Elspeth Jordan, Sarah Pollock, Sharon Stuart, Douglas Thwaites, and Klavdia Vainshtein.

This research was approved by the University of Queensland Medicine Low & Negligible Risk Ethics Sub-Committee (approval #201701092).

Introduction

In late 2017 Mind Australia Limited (Mind) commissioned The University of Queensland (UQ) to conduct a research project, Understanding the factors associated with Australian mental health carers’ employment. The main purpose of this project was a detailed exploration of the factors associated with employment for Australian mental health carers which might be targets to improve carers’ labour force participation, using data from the 2015 Survey of Disability, Ageing and Carers (SDAC). This work builds on and extends previous research conducted by UQ for Mind to profile mental health carers and value their time spent caring in economic terms.

The following summary report accompanies the technical write-up and provides an overview of methods, key findings, and conclusions that can be drawn from the study.

Foreword

It is widely understood - indeed, perhaps self-evident - that people with intensive caring responsibilities are less likely to be employed than ‘non-carers’. Carers not only provide an irreplaceable structural support to Australia’s vast health and social care systems; they also routinely do so at the expense of their own careers, education, and long-term economic security. Unpaid carers in Australia are simultaneously underrepresented in the formal workforce, and an unrecognised part of the health care workforce.

In 2017, Sandra Diminic and her colleagues from the Queensland Centre for Mental Health Research at the University of Queensland published a landmark report that quantified the economic value of Australia’s hidden workforce of unpaid mental health Carers. In 2015, at least 240,000 mental health carers in Australia provided an estimated 208 million hours of informal care, at a replacement cost of $13.2 billion.

In their new report, they advance these findings through a detailed exploration of the disadvantage faced by mental health carers in accessing employment on an equal footing to other Australians, and an examination of the specific barriers many have to workforce participation.

The findings in this latest report are sobering. Mental health carers are significantly more likely not to be employed compared to working age non-carers. Young carers face specific and acute disadvantage, with almost 13% of children aged 5-14 with mental health caring responsibilities not attending school. It is vital that these young carers be identified, and that they receive appropriate support at home and in school, to mitigate against a lifetime of economic and social disadvantage.

The data also indicates cause for cautious optimism. Over 97% of employed primary mental health carers have special working arrangements available, indicating at least partial recognition of their intrinsic value in the workplace by their employers.

The data also points to a potential roadmap for meaningful policy intervention. Over 40% of carers who are not employed would like to work while caring. Better identification mechanisms, and targeted programs to support them in the full complexity of their lives are urgently needed.

This report, together with 2017’s *The Economic Value of Informal Mental Health caring in Australia* reaffirms the need for an integrated and sophisticated policy response across all layers of Government. Workforce participation is a critical part of social identity in Australia. Moreover, the right to work is also a human right, and a fundamental part of what it means to be a valued member of society. Every person should have the opportunity to gain his or her living by work which he or she freely chooses or accepts, and it is high time the Australian government at all levels took proactive steps to safeguard and ensure the realisation of this right for Australia’s growing workforce of unpaid carers.

The solutions needed are multi-faceted and will require the involvement of employers and the private sector, as well as government. New policies and practices are needed that will improve mental health carers’ participation in the workforce. We must do more to enhance and ensure carer inclusion in Australian workplaces. Crucially, as Australia’s population ages, we must invest in the long-term economic security of mental health carers, and indeed all carers.

As I stated in the foreword to the *The Economic Value of Informal Mental Health caring in Australia*, a fundamental issue we must grapple with is how we as a society want to look after and support our most vulnerable – including those with mental health issues and the carers who support them. This research points to the need for a wider cultural change about the value we attach to those who provide unpaid care in Australia.
All Australians have a stake in this debate. This report provides an indication that pragmatic and rational health and social care policies can be remoulded, with a fairer and more equitable reconciliation of ‘work’ and ‘care’ at their core.

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## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>2</td>
</tr>
<tr>
<td>Introduction</td>
<td>2</td>
</tr>
<tr>
<td>Foreword</td>
<td>3</td>
</tr>
<tr>
<td>Contents</td>
<td>5</td>
</tr>
<tr>
<td>Glossary</td>
<td>6</td>
</tr>
<tr>
<td>Background</td>
<td>8</td>
</tr>
<tr>
<td>Aims</td>
<td>9</td>
</tr>
<tr>
<td>Methods</td>
<td>10</td>
</tr>
<tr>
<td>Data source</td>
<td>10</td>
</tr>
<tr>
<td>Definitions</td>
<td>10</td>
</tr>
<tr>
<td>Data analysis</td>
<td>11</td>
</tr>
<tr>
<td>Key findings</td>
<td>12</td>
</tr>
<tr>
<td>1. Employment disadvantage for mental health carers</td>
<td>12</td>
</tr>
<tr>
<td>2. Factors related to employment for mental health carers</td>
<td>15</td>
</tr>
<tr>
<td>3. Caring hours and employment among primary mental health carers</td>
<td>16</td>
</tr>
<tr>
<td>4. Primary mental health carers' needs for support related to employment</td>
<td>17</td>
</tr>
<tr>
<td>5. Vocational engagement of young mental health carers</td>
<td>19</td>
</tr>
<tr>
<td>Conclusions</td>
<td>20</td>
</tr>
<tr>
<td>Recommendations for future research</td>
<td>20</td>
</tr>
<tr>
<td>Implications</td>
<td>21</td>
</tr>
<tr>
<td>References</td>
<td>22</td>
</tr>
</tbody>
</table>
The language used in the disability and caring sector is an evolving landscape, with debate over the most respectful and appropriate terminology. This is particularly relevant to the terms ‘carer’, ‘caring burden’ and ‘care recipient’, which are frequently used among academics and policy makers but not necessarily preferred by all people with a disability, their family members and caregivers. For the purpose of clarity we have chosen to use certain commonly understood key terms throughout this report, as defined below.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Payment and Allowance</td>
<td>Australian Government income support payments for carers. Carer Payment is a means-tested pension available to eligible applicants who provide ‘constant care’ to a person with disability that is either permanent or expected to last more than 6 months. Carer Allowance is a smaller, non-means tested payment in recognition of the caring role.</td>
</tr>
<tr>
<td>Carer/ informal carer</td>
<td>Any person, such as a family member, friend or neighbour who provides regular, ongoing assistance to another person due to a disability or long-term health condition, without receiving a salary, wage or fee for the support provided.</td>
</tr>
<tr>
<td>Caring burden</td>
<td>Caregiver burden refers to the potential physical, psychological, social or financial strain that can be experienced by family members or friends supporting a person with mental illness. This term does not imply that the person with mental illness is themselves a ‘burden’, but rather that the emotional and practical effort and time expended by carers can lead them at times to feel stressed, isolated or exhausted.</td>
</tr>
<tr>
<td>Employment</td>
<td>Engaging in economic work for one hour or more in the previous week. Full-time employment includes permanent, temporary or casual work for 35 hours or more. We classified people as ‘not employed’ if they were unemployed or not in the labour force.</td>
</tr>
<tr>
<td>Mental illness</td>
<td>A health problem significantly affecting how a person thinks, behaves and interacts with others. This covers a range of disorders such as depression, anxiety, psychosis, bipolar disorder, personality disorders and eating disorders. For this report autism, intellectual disability and dementia were not included as ‘mental illness’.</td>
</tr>
<tr>
<td>NDIS</td>
<td>The National Disability Insurance Scheme (NDIS) is a national scheme to provide targeted support and better coordination of, and access to, services for people with disabilities, regardless of their disability type or where they live. The NDIS was launched on 1 July 2013 and is being progressively rolled out in each state and territory.</td>
</tr>
<tr>
<td>Person being cared for/ care recipient</td>
<td>A person who receives regular support or assistance from an informal carer (i.e. a family member, friend or neighbour). The terms ‘person being cared for’ and ‘care recipient’ have been used interchangeably in this report.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Primary carer</td>
<td>The person providing the most unpaid assistance to a person with a disability or long-term health condition. In this report, primary carers were identified as per the 2015 SDAC, and only include co-resident carers aged 15+ years.</td>
</tr>
<tr>
<td>SDAC</td>
<td>The Survey of Disability, Ageing and Carers (SDAC) is conducted by the Australian Bureau of Statistics. The survey collects information on people who may need care and who provide care in Australia. This report used the 2015 SDAC.</td>
</tr>
<tr>
<td>Vocational engagement</td>
<td>Vocational engagement for young carers (&lt;25 years) was defined for this report as participation in either education or employment, including attendance at primary or secondary school, enrolment at a post-secondary institution, or full- or part-time paid employment.</td>
</tr>
<tr>
<td>Young carer</td>
<td>An informal carer aged below 25 years.</td>
</tr>
</tbody>
</table>
**Background**

Mental health carers are the family members, friends and neighbours of people with mental illness who provide ongoing, unpaid assistance to support them with daily living. For people with mental illness, the types of assistance needed are mainly to do with providing emotional support, managing crises and being ‘on call’ in case a situation arises, assisting with household tasks, and coordinating and attending health care appointments. This differs from the types of assistance usually provided by carers to people with physical disabilities, which often involves a more predictable routine and a greater focus on self-care tasks.

Providing this unpaid support can be an important and meaningful part of the relationship between a carer and the person they support, but the amount of time and types of tasks required can also be stressful and potentially burdensome for carers, particularly where they provide a large amount of support over a long period of time. This may in turn affect carers’ own paid employment, leading them to feel stressed and exhausted at work, reduce their working hours to accommodate caring responsibilities, take more leave to care, choose a less desirable job because it is more convenient for caring, or leave the workforce altogether.

For young carers aged below 25 years, there are particular challenges and vulnerabilities. Substantial time commitments to caring for a parent or other relative with a disability can have a negative impact on school and university attendance, completion of assigned work, and age of leaving school during a critical transition period when these young people are developing the foundations of their future careers. The stigma associated with mental illness may also contribute to young mental health carers avoiding social and professional development activities and failing to identify their role in order to access support.

A large number of studies have shown that people with caring responsibilities, regardless of the type of disability, are less likely to be employed than non-carers, although it is not known whether the negative impact of caring on employment is greater for mental health carers. In fact, there has been little Australian research to explore the relationship between caring for people with mental illness and carers’ own employment, or to identify mental health carers who may need assistance in the workforce. Previous studies suggest that less than half of mental health carers are employed, and that a significant proportion make other changes to their work to accommodate caring. Mental health carers also report higher strain and unmet needs from their caring than other carers, and may have different support needs. Such factors could result in more negative effects on employment for mental health carers.

Despite the lack of data, there is a strong rationale for supporting mental health carers to stay in employment. For the carer themselves, time out of the workforce leads to lost income, disruption to their career, and possibly other negative effects such as reduced social networks and poorer health. From a government perspective, the costs include lost tax revenue, increased costs to provide income support (e.g. Carer Payment), and lost productivity when skilled workers reduce their hours or leave the workforce. Recognising these issues, Australia’s Fifth National Mental Health and Suicide Prevention Plan has included an indicator for the proportion of mental health carers in employment. To better support mental health carers in the workforce, we need to know which characteristics identify carers whose employment is at risk, how many of these carers might need support, and what types of assistance would be most helpful for them.
Aims

The aims of this project were to identify:

1. Whether mental health carers are more disadvantaged in employment than carers of people with other disability types and non-carers;

2. Which characteristics of mental health carers and their caring role are most strongly related to their employment, and whether these are unique to mental health carers compared to other carers;

3. The threshold at which the hours of care provided by primary mental health carers are associated with significantly lower employment rates, and whether this differs from other primary carers;

4. The number of Australian primary mental health carers with a possible need for more support to maintain, improve or re-enter employment, their unmet support needs and barriers to employment; and

5. Whether young mental health carers are less engaged in employment and education compared to young people who are not carers or who care for other types of conditions.
Methods

This summary report presents the high-level methods and key findings of the research. Additional technical information about the analyses is available from Mind or the authors by request.

Data source

The following results are based on analysis of the 2015 Survey of Disability, Ageing and Carers (SDAC), a national household survey conducted by the Australian Bureau of Statistics. Carers in the 2015 SDAC were identified by a responsible adult in their household or by a person with disability they supported. Additional personal interviews were completed with all primary carers aged 15 years or more. Information was available from the survey about carers’ current employment and educational enrolment, their personal characteristics, the person they supported, and their caring role.

Table 1. Carer groups for analysis (carers aged 15-64 years)

<table>
<thead>
<tr>
<th>Carer group</th>
<th>Care recipient main condition</th>
<th>2015 SDAC participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Number of carers</td>
</tr>
<tr>
<td>Mental health carers</td>
<td>Mental illness, such as mood, anxiety, psychotic, personality, eating and behavioural disorders.</td>
<td>520</td>
</tr>
<tr>
<td>Other cognitive/behavioural condition carers</td>
<td>Related diagnoses like dementia, autism spectrum disorders, intellectual disability and acquired brain injury.</td>
<td>312</td>
</tr>
<tr>
<td>Physical health with secondary mental illness carers</td>
<td>All other conditions, including cancers, cardiovascular diseases, neurological disorders, sensory disabilities, musculoskeletal conditions, etc. The person being cared for also has another condition which meets the above criteria for mental illness.</td>
<td>577</td>
</tr>
<tr>
<td>Physical health only carers</td>
<td>As above, but the person being cared for does not have a mental illness.</td>
<td>1,455</td>
</tr>
</tbody>
</table>

Definitions

Carers. Due to the structure of the survey dataset, all of the carers in this analysis were living with the person being cared for. In-scope carers for the main study were aged 15-64 years (working age) and provided ongoing support to someone with a disability who was aged 15 years or over. Carers supporting only younger people (<15 years) with mental and behavioural conditions were excluded because the dual impact of parenting and caregiving on employment was too complex to disentangle in this study.

Carers were classified into four groups based on the main disabling condition of the person they supported, as shown in Table 1. Where the carer supported more than one person, conditions were classified hierarchically from the top down (i.e. mental illness first).
Primary carers. Primary carers in the 2015 SDAC were separately identified as a subset of the broader carer group, as the carer providing the most unpaid assistance to a person with disability.

Young carers. The young carers analysis included carers aged 5-24 years, and examined broader vocational engagement, including with education.

Non-carers. We included a comparison group of non-carers of the same age as the relevant carer group. These non-carers were people not providing any informal care.

Employment. In the 2015 SDAC, being employed was defined as engaging in economic work for one hour or more in the survey reference week. Full-time employment included permanent, temporary or casual work for 35 hours or more. We classified carers as ‘not employed’ if they were unemployed but looking for work, or were not in the labour force (including due to other reasons such as retirement or child care).

Vocational engagement. Vocational engagement for young carers aged 5-14 years included whether they were attending primary or secondary school. For young carers aged 15-24 years, we classified vocational engagement into three levels: (1) full-time study (secondary school or post-secondary institution) or full-time employment; (2) part-time employment and/or study; and (3) not employed or studying (including other roles such as caring for someone with a disability or child care).

Data analysis
We used survey weights in the 2015 SDAC provided by the ABS to produce percentages and population estimates representative of the total Australian population. Numbers shown in the error bars or brackets of figures throughout this report represent the 95% confidence intervals around each estimate. Chi-square tests were conducted for comparisons between mental health versus other carers and mental health carers versus non-carers.

We also conducted a series of multivariate logistic regression analyses to look at the relationship between carer and caring role characteristics and whether carers were currently employed, controlling for differences between carers for different conditions. The initial models considered the following factors: carer sex, age group, marital status, rurality, country of birth, highest level of education, whether the carer had a disability, whether they were the primary carer, number of persons being cared for, caring for a close family member (spouse/partner or adult child), caring for someone with a profound or severe limitation in core activities, and whether any person being cared for also received formal assistance from services for their disability (type, frequency and unmet need). For primary carers, we also included their weekly hours of care and the number of years they had been caring.
Key findings

1. Employment disadvantage for mental health carers

In 2015, 42.3% of working age mental health carers were not employed (Figure 1). Those who were not working reported a range of roles, including informal caring, home duties or child care, study and being retired or permanently unable to work. Mental health carers were significantly more likely not to be employed (42.3%) compared to working age non-carers (24.0%). There were no differences in employment rates between mental health carers and other carers.

Figure 1. Employment status of carers (15-64 years) for adults with mental illness, Australia 2015

- Employed part-time: 24.7% (20.7-29.1)
- Employed full-time: 33.1% (28.1-38.4)
- Not employed: 42.3% (36.6-48.1)
- Study: 4.8% (3.0-7.5)
- Caring: 7.2% (5.1-10.1)
- Retired/unable to work: 9.3% (6.9-12.5)
- Home duties: 11.7% (8.6-15.6)
- Other: 9.3% (6.9-12.3)

- Caring for ill, disabled or elderly person
- Retired, voluntarily inactive or permanently unable to work (e.g. due to own disability)
- Home duties or caring for child(ren)
- Attending an educational institution
- Other: travel or leisure activity; unpaid voluntary work; own illness or disability; other unspecified activity
Box 1 describes some other key employment characteristics of mental health carers.

**Box 1 – Employment characteristics of mental health carers**

**Working hours**
- 17.2% of employed mental health carers worked 1-15 hours, 25.5% 16-34 hours, 32.9% 35-40 hours, and 24.3% 40+ hours per week.
- Employed mental health carers were more likely to be working <16 hours per week (17.2%) than non-carers (11.7%). There were no differences between mental health versus other carers.

**Industry of employment**
- 36.3% of employed mental health carers worked as a manager or professional; 41.1% in a technical, trade, service, sales or clerical role; and 22.6% as a machinery operator or driver, or labourer.
- Mental health carers (22.6%) were more likely than non-carers (15.7%) to be employed as a machinery operator, driver, or labourer rather than a technical or professional role. There were no differences between mental health versus other carers.
More female than male mental health carers worked part-time or were not employed (Figure 2). A larger proportion of female carers reported their main activity as home duties or retirement.

Figure 2. Employment status of carers (15-64 years) of adults with mental illness, by sex, Australia 2015

Among the subgroup of primary mental health carers, there was additional information available on the impact of caring on their employment. For primary mental health carers who were either currently employed or had worked prior to commencing caring, more than half reported negative impact of caring on their working hours: 26.4% had stopped working altogether to care, and a further 25.8% had reduced their working hours.
2. Factors related to employment for mental health carers

Box 2 shows the carer and caring role characteristics which were significantly related to not being employed for female and male mental health carers. In addition to the factors outlined below, male carers were also more likely to be employed if the person they cared for received formal assistance specifically with cognitive or emotional tasks (but not other practical or self-care tasks), or if the person they cared for received formal assistance at least weekly.

<table>
<thead>
<tr>
<th>Female carers (n=268)</th>
<th>Male carers (n=238)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age (&lt;35 or 55+ years)</td>
<td>• Carer has a disability</td>
</tr>
<tr>
<td>• Lower educational attainment</td>
<td>• Care recipient has a more severe impairment</td>
</tr>
<tr>
<td>• Carer has a disability</td>
<td>• Care recipient does not receive any formal (paid) assistance</td>
</tr>
<tr>
<td>• Care recipient has more severe impairment</td>
<td></td>
</tr>
</tbody>
</table>

The factors related to employment for female and male mental health carers (as outlined in Box 2) were compared to those for other disability carers. For female carers, there were no significant differences between the two groups in which characteristics were important. For male carers, there were also no significant differences between the two groups. There was a pattern suggesting that the level of impairment of the person being cared for and their receipt of formal assistance could be more important for mental health carers than other carers, but this did not reach statistical significance.
3. Caring hours and employment among primary mental health carers

This section focuses on just primary mental health carers, since weekly hours of care were only recorded for primary carers in the 2015 SDAC. The majority of primary mental health carers (57.5%) provided less than 30 hours of care per week. There was an inverse relationship between hours of care and employment status for primary carers, with lower rates of employment among carers providing more hours of support (Figure 3).

Figure 3. Employment status of primary carers for mental illness and other disabilities, by weekly hours of care provided, Australia 2015

<table>
<thead>
<tr>
<th>Weekly Hours of Care</th>
<th>Employed</th>
<th>Not employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-19 hours</td>
<td>0.65</td>
<td>0.35</td>
</tr>
<tr>
<td>20-39 hours</td>
<td>0.51</td>
<td>0.49</td>
</tr>
<tr>
<td>40+ hours</td>
<td>0.19</td>
<td>0.81</td>
</tr>
</tbody>
</table>

After controlling for carer’s sex and disability status, primary mental health carers had significantly lower employment rates if they were providing 40 or more hours of care per week compared to less than 10 hours. When a range of different thresholds for caring hours were tested (10+, 20+, 30+, 40+, 60+ hours), all cut-off levels showed a significant relationship between higher hours of care and lower employment rates.

The inverse relationship between hours of care and employment status was present for both primary mental health carers and primary carers for other conditions (see Figure 3). There was no significant difference in the relationship between hours of care and employment for primary mental health carers versus primary carers of other types of disabilities. Although in Figure 3 it appears that the percentage of mental health carers providing 40+ hours of care who were employed (19.0%) is much lower than that for other carers (30.4%), the small numbers of mental health carers in this group led to a wide uncertainty range around the estimate which could overlap with the result for other carers (see error bars in Figure 3).
4. Primary mental health carers’ needs for support related to employment

We estimated the number of primary mental health carers with a possible need for more support to maintain, improve or re-enter employment. Box 3 describes the key indicators available in the 2015 SDAC that were used to quantify carers with a possible unmet need for employment support.

**Box 3 – Indicators of a possible need for employment support, 2015 SDAC**

**Employed carers**

1. Provided 40 or more hours of care per week; OR
2. Had reduced their working hours to commence their caring role; OR
3. Worked part-time and wanted to work more hours; OR
4. Wanted more use of special working arrangements.

**Carers who were not employed**

1. Had left employment to commence their caring role; OR
2. Reported wanting to work while caring.

As shown in Figure 4, just over half of working-age primary mental health carers had a possible need for more support to maintain, improve or re-enter employment based on the available indicators. A further 3,116 employed primary mental health carers had used special working arrangements to care for someone in the past 6 months but did not meet any of the above indicators of current unmet need.

**Figure 4. Weighted population estimates of the number of primary mental health carers with possible support needs, Australia 2015**
Box 4 provides further information about the self-reported barriers to employment and unmet support needs of primary mental health carers. Special working arrangements described for employees in the 2015 SDAC included paid and unpaid leave, flexible hours, and other arrangements with employers.

<table>
<thead>
<tr>
<th>Box 4 – Unmet support needs and barriers to employment for primary mental health carers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Special working arrangements (employees)</strong></td>
</tr>
<tr>
<td>• 97.3% of employed primary mental health carers had special working arrangements available.</td>
</tr>
<tr>
<td>• 46.6% had made use of these in the past 6 months to care for someone.</td>
</tr>
<tr>
<td>• 12.1% reported wanting more use of special working arrangements.</td>
</tr>
<tr>
<td><strong>Barriers to employment (if not working)</strong></td>
</tr>
<tr>
<td>• 42.2% of carers who were not employed said they would like to work while caring.</td>
</tr>
<tr>
<td>• The main reported barrier to re-entering the workforce was that there were no alternative care arrangements available or it would cause disruption to the main person they cared for (46.5%).</td>
</tr>
<tr>
<td>• Workforce-related issues like working hours, available jobs, the carer’s age, lack of experience, or loss of skills were reported as the main barrier by a minority of carers who wanted to work (22.9%).</td>
</tr>
</tbody>
</table>
5. Vocational engagement of young mental health carers

Of 537 young carers aged 5-24 years in the 2015 SDAC, 14.6% were caring for an adult with mental illness. Just under half (48.9%) of young mental health carers were aged 20-24 years. Most young mental health carers were male (68.3%), whereas for young carers of other disability types the gender ratio was more even. The majority of young mental health carers lived in a major city (63.5%), were born in Australia (85.1%), and cared for their parent (72.4%).

Box 5 describes the vocational engagement of young mental health carers aged 5-24 years in the 2015 SDAC.

**Box 5 – Education and employment of young mental health carers (5-24 years), Australia 2015**

**5-14 Year olds**
- 87.2% of mental health carers aged 5-14 years were attending primary or secondary school.
- Significantly fewer mental health carers attended school compared to other carers (100%), but not non-carers (95.7%).
- The number of carers in this age group was small, producing large margins of error around the above percentage estimates; hence they should be interpreted with caution.

**15-24 Year olds**
- 54.0% of mental health carers aged 15-24 years were either employed or studying full-time.
- 17.4% were in part-time employment and/or were studying part-time.
- 28.6% of mental health carers were not studying or working. This was significantly higher than for other carers and non-carers of the same age (Figure 5).

**Figure 5. Percentage of 15-24 year olds in education or employment by caring status, Australia 2015**
Conclusions

Recommendations for future research

This study used the 2015 SDAC, a large and nationally representative survey which includes information about the conditions of people being supported by carers, as well as a range of other useful questions. The survey is a snapshot of one point in time, so the results are not able to confirm whether any of the factors related to carers’ employment directly caused that employment status. However, previous research on other carer groups has followed carers over time and shown that many of these factors predict whether carers later leave the workforce. Unfortunately, available Australian longitudinal studies which include carers do not record the condition of the person being cared for, meaning that the 2015 SDAC is one of few national data sources for mental health carers. It is recommended that questions about the condition of the person being cared for be added to recurrent surveys such as the Household, Income and Labour Dynamics in Australia (HILDA) Survey or the Australian Longitudinal Study on Women’s Health to allow for future longitudinal studies of mental health (and other) carers.

For practical reasons, the analysis excluded carers who do not live with the person they support, and people caring for children with a mental illness. Carers not living with the person being cared for may also face significant challenges in balancing their caring and employment, including the need to travel to support that person. Many of the patterns seen in this study may be similar for non-resident mental health carers, but this cannot be confirmed until further data is available to better understand employment for this group.

There were also significant limitations to the young carers analysis due to small sample sizes and the limited information collected for people aged below 15 years. There are very few studies of carers in this younger age group because of the difficulties in recruiting young research participants and in identifying ‘hidden carers’. Since the results of this project suggest significant vocational disadvantage among young people caring for an adult with mental illness, future attempts to focus research on this population would be enlightening.

Other restrictions in the types of questions asked in the 2015 SDAC led us to make assumptions in estimating whether primary carers might have a need for more support in their employment. We did not have access to a direct measure of need for employment support, and these carers may have been in their current employment and caring situation for a long period of time. The 2015 SDAC did not include carers’ work history, absenteeism, presenteeism, workplace stigma or subjective distress related to employment. There are likely to be impacts of mental health caring on a number of these areas which could be explored in future research.

These recommendations for further research are summarised in Box 6.

Box 6 – Areas for further research

- Record the condition of the person being cared for in Australian longitudinal surveys of carers, and replicate this report’s findings in a follow up study.
- Examine employment disadvantage and factors related to employment for mental health carers who do not live with the person they support.
- Confirm these provisional findings of vocational disadvantage for young mental health carers in a larger sample, particularly of carers aged <15 years.
- Look at the relationship between mental health caring and other areas of employment, such as workplace stigma and work-related stress.
Implications

The main implications of this study are summarised in Box 7.

Box 7 – Key messages

• Despite national progress in recognising and supporting carers, mental health carers are still disadvantaged compared to non-carers in their participation in employment, working hours, and occupational level. More than half of primary carers reduced their hours or left employment to commence caring.

• Mental health carers are more likely to be employed if the person they care for is less disabled, if they provide fewer hours of support, and if the person with mental illness also receives assistance from organised services.

• Female mental health carers are less likely to be working than male carers, and their employment status is more related to their own characteristics (such as age and education) than for male carers, where the caring role seems more important. This is likely explained in part by women’s greater role in home duties and child care.

• Young mental health carers have lower rates of engagement with education and employment than other young carers and non-carers, suggesting that better identification and support of these young people may be needed to prevent later career disruption.

• There were few identified differences in employment between mental health carers and other carers, and these were specific to young carers <25 years. The degree of impairment of the person being cared for, available supports and the carer’s own circumstances seem to be more important for their employment than the nature of caring tasks. Therefore a standard approach to employment supports for all carers may be appropriate, although other aspects like job stress warrant further research.

• Roughly half of primary mental health carers were identified as having a possible need for support to maintain or improve their current employment or to re-enter the workforce.

• The main barriers to working for primary mental health carers who were not currently employed centred on meeting the needs of the person with mental illness rather than the suitability of the workforce or carers’ skills.

• Improving the availability and effectiveness of psychosocial support services for people with mental illness may therefore assist their carers to maintain or re-enter employment, and may be more critical than access to employment services. There are opportunities in the current roll-out of the National Disability Insurance Scheme (NDIS) to address this through improving the range of supports available, as well as significant potential barriers.30 Key problems identified to date include greater difficulty accessing needed services for people with psychosocial disability compared to other conditions, and carer supports needing to be requested by the person with a disability.32 Further, not all people with mental illness are eligible for support through the NDIS and some who are eligible may ‘fall through the cracks’33,34, meaning alternative solutions are needed to fully support them and their carers.

• Given the clear benefits to mental health carers and society from their participation in employment,19,21,35, it is critical that current and future reforms do not reduce the level of support available for carers and people with psychosocial disabilities. While some carers will choose not to work and most will continue to provide significant support, improving the availability, quality and continuity of mental health support services would help take the pressure off carers and allow them to better manage their multiple roles.7,14,36


